
Study of the Unmet Needs of Adults with Disabilities in Massachusetts, 2007

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Bureau of Community Health Access and Promotion
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Executive Summary

Introduction and Background

The Massachusetts State Legislature made funding available for the Massachusetts Department of Public Health (MDPH) to support research activities to determine the need for home and community-based services and to create an economic profile of adults with neurological and physical disabilities and their families. MDPH contracted with the Center for Survey Research, University of Massachusetts Boston (CSR), to conduct the study. In a unique effort to look at an underserved group, this study is designed to consider the unmet needs of adults age 18-59 years with disabilities.

The MDPH and CSR agreed that for this study, using a sub-sample of a statewide random digit dial sample representative of Massachusetts households would be the most efficient and cost effective design. The Massachusetts Behavioral Risk Factor Surveillance Systems (BRFSS), the sample from which this study was taken, is described in detail in Appendix A, along with a detailed description of the survey methodology and the exact criteria for selection into the study.

An important caveat regarding the sample is to understand that it very likely under-represents the population of adults with disabilities in the state and, thus, understates the full set of potential needs of this group. This data collection effort was designed as an initial attempt to survey this population, an exploration of what we could learn about the unmet needs of persons with disabilities. This report represents CSR's perspective on what the data tell us about the unmet needs of adults with disabilities in Massachusetts. This report is based on 571 interviews and presents the main quantitative findings from weighted frequencies of the survey data.

Description of Interview Participants

Demographics

- There were more female survey respondents (60%) than male (40%). The average age of respondents was nearly 45 years, and most respondents (90%) identified themselves as White. In general, the survey participants had some college or higher education (71%). Over three-fourths of respondents (78%) lived with at least one other adult, and about 40% had a child, age 17 years or younger, living with them.

Employment

- Half of the survey respondents (51%) reported working at a job for pay.
- For the half who was not working for pay, over 80% said that they were not working or stopped working because of their health condition or disability.

Health Insurance

- Almost all respondents (98%) reported having some type of health insurance.
- Over half (57%) reported having private health insurance only.
- Two of five respondents reported coverage under some kind of government program.

Disability Status

- Most respondents were not new to their health condition or disability – nearly half (48%) estimated that they had had their condition for more than five years. Nine of ten respondents reported that their health condition or disability began after age 18.
- The survey contained a number of questions about respondents' difficulties with Activities of Daily Living (ADLs) and Instrumental Activities of Daily Living (IADLs). The greatest number of reports of difficulty, and the activities for which they were most likely to report receiving help, were typically the IADLs, including heavy housework and shopping. The fewest reports of difficulty were for eating and using the toilet.
- On average, respondents reported having difficulty with less than one ADL and about one and a half IADLs, for a combined average of about two ADLs/IADLs.
- While all respondents met the survey's definition of having a disability, only three-fourths (74%) described themselves as having a disability of some kind, when asked in a direct question.

General Health

- Over one-third of respondents (37%) described their health as fair or poor, with just one quarter reporting excellent or very good health.

Unmet Needs

ADLs and IADLs

- Housework is the area in which the most respondents reported needing help or more help. About half of those having difficulty with heavy housework reported needing more help, and over half of those having difficulty with light housework also reported needing more help.
- There appear also to be unmet needs for other IADLs, including shopping, meal preparation, and managing money.
- Respondents had lower reported need for more help with most of the ADLs, the exceptions being the two ADLs related to mobility (walking and getting in or out of bed or chairs).

Assistive Technology

- About 11% of respondents said that there is equipment that they need for their health condition or disability that they do not have, and nearly nine out of ten of them (89%) said that the reason they were not able to get the equipment they needed was the cost or that insurance would not cover it.
- Approximate out-of-pocket expenses in the past 12 months for equipment ranged from zero to \$7500, with a mean of about \$513.
- When asked how difficult it was to afford these expenses, about two in five said it was very or somewhat difficult (41%).

Adapting Environment

- About 13% of respondents reported ever needing some adaptation to their homes, and about half of them (45%) reported currently needing the adaptations (or more of them) to be done. Most (89%) respondents needing work done reported cost as a factor.
- About three-fourths of those needing adaptations said they would like more information about how to pay for them.

Home Care

- Three of five respondents (about 61%) reported that they receive no in-home help at all.
- For those who receive in-home assistance, informal care was reported much more frequently than formal care from an agency or paid care or professional nursing care. About 32% of respondents receive informal care only, about 2% receive formal care only, and about 6% receive both kinds of care.
- Respondents who reported receiving informal care in their homes from family or friends who live with them received about 17 hours of this kind of help per week in a typical week. Respondents who reported receiving informal care from people who do not live with them received about 11 hours of this kind of care per week in a typical week.
- The respondents who reported receiving formal care from an agency, paid person, personal care assistant or attendant, or a volunteer reported receiving about 11 hours of this kind of care per week in a typical week.
- About 7% of respondents receiving no in-home care said that they need help with health care, personal care, or tasks of daily living.
- One-third of the respondents who already receive some help at home said that they could use more help.
- Most respondents who currently receive in-home help of some kind did not spend anything for that care (79%), but respondents who did spend something reported spending on average \$298 for that care in the past 12 months. About 58% of those who did have out-of-pocket care expenses reported that this spending was very or somewhat difficult.

Case Management

- There appears to be a fairly high need for case management kinds of services, including help finding services (20%), help keeping track of services (20%), advice about eligibility for public benefit programs (18%), and help finding caregivers to help at home (15%).

Access to Care

- About 20% of respondents said that they did not see a primary care provider when they needed to in the past 12 months, and about 20% said they did not see a medical specialist when they needed to in the past 12 months. About 19% said they did not see a mental health worker when they needed to in the past 12 months.
- Eight percent of respondents reported that their health condition or disability resulted in problems getting the health care they needed in the past 12 months. About one-third of them (35%) said that the provider was not knowledgeable about the disability. About one-fourth of them (26%) said that the equipment at the health care facility was not accessible, and 12% said that the site itself was not physically accessible. Approximately 17% said the provider could not communicate with them.

Hospital, Nursing Home, Rehabilitation

- One-third of all respondents (33%) were hospitalized for at least one night in the past 12 months.
- About 6% of respondents said they or their doctor thought they needed hospitalization in the past 12 months, but they were not hospitalized.

Physical and Occupational Therapy

- About one-third of respondents (34%) saw a physical or occupational therapist in the past 12 months; however, about one-fourth of them (26%) said that they did not get as much therapy as they needed.
- About 8% of respondents said they did not get needed physical or occupational therapy.

Prescription Drugs

- Almost nine of ten respondents (87%) reported taking prescription medication. About 13% of respondents reported that there is a medication that they need but do not get.
- On average, respondents spent nearly \$5500 out of pocket in the past 12 months for their medications, with over 60% of them spending in excess of \$1000 per year.
- While about half of respondents said that it was not difficult at all to afford out-of-pocket payments for prescriptions, about 30% said it was very or somewhat difficult.

Work Accommodations

- About half of the survey respondents were employed for pay at the time of survey administration. Of those, nearly one-third (33%) reported that their health condition or disability made it very or somewhat difficult to work in their job.
- About one-third of the currently employed (33%) reported that they had needed their employer to make accommodations because of their health condition or disability. Among those needing any accommodation, about three-fourths (75%) reported that their employer had done most or all of what they could do. About one in ten said their employer had done none of what they could do.

Other Needs: Home-Delivered Meals, Information, Transportation

- Fewer than 1% of respondents reported that they received home-delivered meals. Among the majority that did not receive home-delivered meals, about 5% said that they felt like they need them.
- About one-third of respondents (34%) reported that they wanted to get information about services for people with a health problem or disability but did not know where to get it. One-fourth of respondents (25%) said that they wanted information about legal rights for people with their health problem or disability but did not know where to get it.
- About 17% of respondents reported having had a transportation problem getting where they needed to go in the past 12 months. Most of that group (77%) said it has been very or somewhat difficult getting where they would like to go.

Introduction and Background

The Massachusetts State Legislature made funding available for the Massachusetts Department of Public Health (MDPH) to support research activities to determine the need for home and community-based services and to create an economic profile of adults with neurological and physical disabilities and their families.¹

MDPH contracted with the Center for Survey Research, University of Massachusetts Boston (CSR), to conduct the study. MDPH and CSR, in collaboration with the Disability Policy Consortium (DPC) and the Home and Community-Based Services Committee of the DPC, designed and developed the study. The objective of the study was to examine the unmet needs for home and community-based services for people with disabilities who fall in the age gap between children (under age 18) and older adults (age 60 and over), two groups who are known to have more coverage. In a unique effort to look at this underserved group, this study was designed to consider the unmet needs of adults age 18-59 years with disabilities.

The funding for this initial study was not sufficient to conduct a stand-alone data collection that is fully representative of the state population of adults age 18-59 with disabilities. The costs to screen for and identify such a sample are prohibitive. Therefore, we considered a number of options for studying this population, including sampling from lists of members of different disability organizations, such as the Multiple Sclerosis Society, the Parkinson's Association, and the Spinal Cord Injury Association. The MDPH and CSR agreed that for this study, using a sub-sample of a statewide random digit dial sample representative of Massachusetts households would be the most efficient and cost effective design. The Massachusetts Behavioral Risk Factor Surveillance System (BRFSS), the sample from which this study was taken, is described in detail in Appendix A, along with a detailed description of the survey methodology.

An important caveat regarding the sample is to understand that it very likely under-represents the population of adults with disabilities in the state and, thus, understates the full set of potential needs of the group. Individuals with the most severe limitations were not included in this study because the BRFSS does not include individuals living in institutions. In addition, the BRFSS methodology precludes anyone from assisting the selected respondent in completing the interview if the selected adult had difficulty in participating for any reason. Other limitations of the BRFSS methodology are described in Appendix A.

This data collection effort was designed as an initial attempt to survey this population, an exploration of what we could learn about the unmet needs of persons with disabilities. The goal was to do a baseline data collection on this topic with the expectation that the findings would suggest areas for further study in a more intensive data collection effort. This report is the culmination of the project and represents CSR's perspective on what the data tell us about the unmet needs of adults with disabilities in Massachusetts.² The report presents the main quantitative findings of the survey.

¹ Following is what the 2006 state legislation made available: *"Provided further, that \$120,000 shall be expended for a study for home and community based services and an economic profile of individuals and families with neurologically and physically disabled adults under 65; and provided further, that said study shall be one-time in nature and shall not result in any annualization in fiscal year 2007."*

² There is a separate report about the caregivers' outlook about the unmet needs of the people they care for as well as their unmet needs as caregivers.

Findings

This report is based on 571 interview participants. Survey participants were Massachusetts adults, age 18-59, who reported in the BRFSS that they had a health condition or disability that limited their activities or required them to use special equipment and agreed to be contacted for a follow-up survey. The study also included respondents who self-identified as having physical, mental, emotional or communication-related disabilities. Only respondents who answered the BRFSS in English were eligible for inclusion. The exact criteria for selection into the study are described in Appendix A. The first part of this report describes their health, the extent and nature of the disability, health insurance, employment, and demographics. The second part of the Findings section is more specific to the questions this survey was designed to address: the needs that adults with disabilities have that are not sufficiently covered. All of the results reported here are based on weighted data, described in the weighting section of Appendix A.

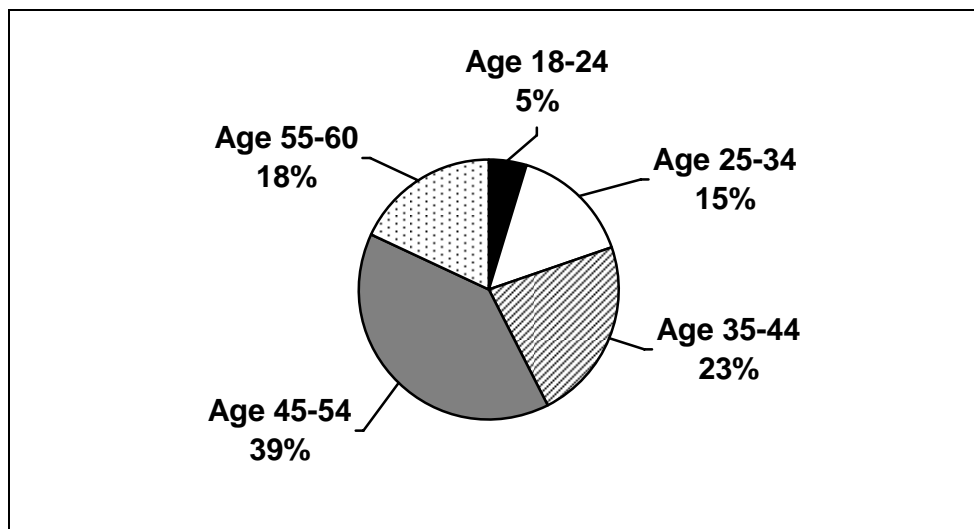
Description of Interview Participants

As was expected, the adults with disabilities who were interviewed varied widely in terms of their health status, type of disability, severity of disability, and demographics. As such, there does not appear to be a “typical” respondent, but there are some patterns that emerge, which are covered in the following narrative.

Demographics

There were more female survey respondents (60%) than male (40%), consistent with other data collections and known survey literature. Over half of respondents (55%) were currently married. To be eligible for this survey, respondents needed to be 18-59 years old at the time of the BRFSS administration (a few had turned 60 by the time of the current interview). Given the disability eligibility criteria, it is not surprising that the ages tended towards the higher end of the age range. The average age of respondents was nearly 45 years, with fewer respondents in the younger age groups. The following chart shows the age group distribution.

Figure 1. Age Distribution

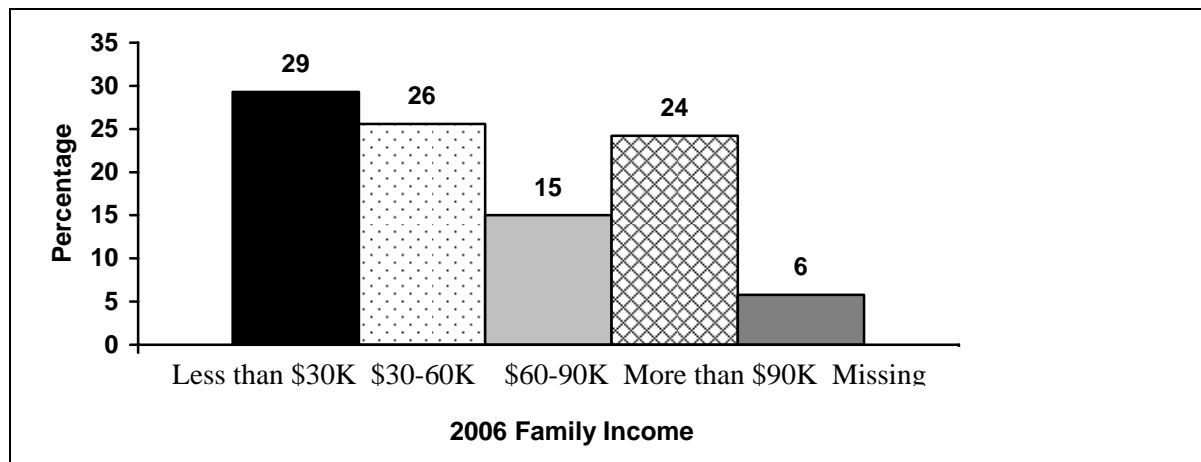


Most respondents (89%) identified themselves as non-Hispanic White, with a small number reporting Hispanic (3%), non-Hispanic Black (3%), Asian (3%), American Indian or Alaska Native (3%), or something else (4%). (Respondents could report more than one race, which is why the percentages total to more than 100.)

In general, the survey participants had some college or higher education (71%). Only 6% reported less than a high school diploma, and another 22% reported that a high school diploma was their highest degree.

Income was fairly evenly distributed among the groups shown in this chart.

Figure 2. Household Income Distribution



Most survey respondents (66%) lived in houses and the rest lived in apartments or condominiums. Over three-fourths (78%) lived with at least one other adult, and about 40% had a child, age 17 or younger, living with them. Table 1 summarizes respondents' living situations.

Table 1. Living Situations

	% (n=570)
Live with adults only	45.3
Live with children and adults	32.7
Live alone	14.2
Live with children only	7.9

Employment

Half of the survey respondents (51%) reported working at a job for pay, but the remaining respondents, all of working age, were not currently working for pay. Those who were working reported working an average of 37.5 hours per week, ranging from just 3 hours per week to as many as 85 hours per week, with most reporting a 40-hour work week. For the half who were not working for pay, over 80% said that they were not working or stopped working because of their health condition or disability (in whole or in part).

Health Insurance

Almost all (98%) survey respondents reported having some type of health insurance. Table 2 summarizes the health insurance status of respondents. Over half (57%) reported having private health insurance only. Two of five respondents reported coverage under some kind of government program – CommonHealth, MassHealth, Medicaid, Medicare, veterans’ coverage, or some other government program. About one-fourth of those covered by a government program also had private insurance or a medigap plan.

Table 2. Health Insurance Coverage

	% (n=569)
Private insurance only	57.3
Public insurance only	30.5
Both public and private	10.0
No health insurance	2.1

Disability Status

While all respondents met the survey’s definition of having a disability, only three-fourths of them (74%) described themselves as having a disability of some kind, when asked in a direct question. Over 90 percent of respondents said that they were limited because of a physical, mental, or emotional problem, over one-fourth (28%) reported using special equipment, and nearly four in ten (39%) reported having trouble learning, remembering, or concentrating. Most respondents were not new to their health condition or disability – nearly half (48%) reported having had their condition for more than five years. Nine of ten respondents reported having had their health condition or disability since age 18 years. About 4% reported having had their disability since birth, and 7 reported that their condition began between birth and age 17 years. The majority of respondents can be described as having an adult-onset disability.

The survey contained a number of questions about respondents’ difficulties with Activities of Daily Living (ADLs, including bathing and showering, dressing, eating, getting in or out of bed or chairs, walking, and using the toilet) and Instrumental Activities of Daily Living (IADLs, including doing light housework such as light cleaning, straightening up and washing dishes, doing heavy housework, preparing meals, shopping, and managing money). As shown in Table 3, the fewest reports were for having difficulty eating and using the toilet. The greatest number of reports, and the activities for which they were most likely to report receiving help, were typically the IADLs, including heavy housework and shopping. More than half of respondents reported having difficulty doing heavy housework and over one-third reported receiving help. On average, respondents reported having difficulty with less than one ADL and about one and a half IADLs, for a combined total of about two ADLs/IADLs.

General Health

Over one-third of respondents (37%) described their health as fair or poor, with just one quarter reporting excellent or very good health. About one in five (21%) reported that their health limited their social activities most or all of the time in the past month, and another two in five (44%) reported that their health limited their social activities some of the time in the past month.

Table 3. ADLs and IADLs – having difficulty and receiving help (based on full sample)

	Have any difficulty (n=571)*	Receive help with (n=571)
ACTIVITIES OF DAILY LIVING		
Walking	26.8%	8.8%
Getting in or out of bed or chairs	16.9%	8.6%
Bathing or showering	11.2%	5.2%
Dressing	8.6%	6.2%
Eating	4.8%	3.1%
Using the toilet	4.3%	1.3%
INSTRUMENTAL ACTIVITIES OF DAILY LIVING		
Heavy housework	53.8%	38.4%
Shopping	31.4%	25.3%
Light housework	25.8%	17.1%
Managing money	19.5%	13.5%
Preparing own meals	14.2%	11.5%

* The number of unweighted cases varies from 568-571, depending on the number of missing cases.

Unmet Needs

The goal of the study was to describe and quantify possible unmet needs of adults with disabilities. The survey measured unmet needs in a number of ways, including questions about specific activities for which the person might need help as well as general questions about needing help or more help.

ADLs and IADLs

Table 4 shows the percentage of respondents who said that they needed more help with ADLs and IADLs.³ The first column shows the percentage of those having difficulty with that ADL or IADL who reported needing more help. The second column is based on the full sample, which gives an indication of the magnitude for the population as a whole, not just for those having difficulty with that particular activity.

Table 4. ADLs and IADLs – need more help

	Need more help with	
	Based on those having difficulty*	Based on the full sample (n=571)
ACTIVITIES OF DAILY LIVING		
Getting in or out of bed or chairs	33.2%	5.6%
Using the toilet	32.1%	1.3%
Walking	28.5%	7.6%
Bathing or showering	27.4%	3.1%
Dressing	14.1%	1.1%
Eating	3.3%	0.1%
INSTRUMENTAL ACTIVITIES OF DAILY LIVING		
Light housework	52.5%	13.6%
Heavy housework	50.8%	27.3%
Preparing own meals	49.1%	7.1%
Shopping	36.9%	11.6%
Managing money	34.6%	6.7%

* The number of unweighted cases varies depending on how many respondents reported that they had difficulty with a particular ADL/IADL. The numbers vary from 21 (for help eating) to 354 (for heavy housework).

Housework was the area in which the most respondents reported needing more help. About half of those having difficulty with heavy housework, such as washing floors or windows, reported needing more help, representing over one-fourth of respondents in the full sample. Likewise, over half of those having difficulty with light housework, such as washing dishes or straightening up, reported needing more help with that, but that represents a lower percentage of

³ Respondents who said they had difficulty with an activity and already received some help were asked if they needed “more help than they currently receive”; those who reported having difficulty with an activity but did not currently receive help were asked if they needed help. Their responses are combined as needing more help.

the full sample (about 14%). Respondents had lower reported need for more help with most of the ADLs, the exceptions being the two ADLs related to mobility (walking and getting in or out of bed or chairs).

Assistive Technology

Based on a number of specific questions about equipment use, about two-thirds of respondents (68%) did not report using any special equipment for their health problem or disability.⁴ Among respondents who reported not using any special equipment, 8% reported that there was special equipment that they needed for their health condition or disability but did not have. Among the one-third of respondents who already reported using equipment for their health condition or disability, 18% reported that there was any additional equipment they needed. In total, about 11% of respondents overall said that there is equipment that they need but do not have. When asked what equipment they needed, respondents reported a variety of things ranging from hold bars in the bathroom, shower stools, and orthotics to things that are very expensive and harder to obtain such as scooters, stair lifts, adapted computers, and adjustable beds.

Respondents who reported using a wheelchair, scooter, or accessible vehicle were asked about equipment repairs in the past 12 months that may have left them without a way to get around. Over two-thirds of the respondents who reported needing a repair in the past 12 months (70%) said that during the time of the repair, they were without a way of getting around. However, not very many respondents reported needing repairs, so the number reporting that they were without a way of getting around is actually a small percentage of the population of adult disabled (about 1% of the sample as a whole).

Respondents who reported needing equipment they did not have for their health condition or disability were asked why they were not able to get the equipment they needed. Nearly nine out of ten (89%) reported equipment cost or noncoverage of the equipment by their insurance as barriers. Other reasons for inability to obtain needed equipment included lack of knowledge about where to get the equipment, unavailability of the equipment in their community, or their own lack of effort to obtain the equipment.

Respondents who used equipment for their health condition or disability were asked their approximate out-of-pocket expenses for the equipment during the past 12 months. Reported costs ranged from zero to \$7500, with a mean of about \$513, including the half of respondents who said they had no out-of-pocket equipment expenses in the past year. When asked how difficult it was to afford these expenses (if they had any), about two in five said very or somewhat difficult (41%) and about three in five (59%) said a little difficult or not difficult at all.

Adapting Environment

About 13% of respondents reported ever needing some adaptation to their homes, and about half of them (45%) reported currently needing the adaptations (or more of them) to be done. Respondents reported a number of reasons why the adaptations have not been done, including cost (89% of respondents needing work done), living in a rental unit that cannot be changed

⁴ The number of reports is somewhat different when respondents were asked the single screener question about equipment use. That rate was closer to three-fourths than two-thirds.

(15%), or inability to adapt the structure (20%). Among those needing some adaptation, about three-fourths (74%) reported that they would like more information about how to pay for adaptations. These percentages, based on just those who said they ever needed some adaptations to their home, represent a fairly small percentage of the total pool of respondents. Specifically, of the total sample, about 6% of respondents said that they currently need some adaptation to their home, 5% of the total sample said they have not had the adaptation done because of the cost, and about 4% said they would like more information about how to pay for adaptations.

Home Care

As shown in Table 5, the survey contained questions about four different sources of in-home help. The first two kinds of care – from spouse, family, or friends living with them and from family, friends, neighbors not living with them – are considered informal care, and the other two types are formal care. As shown in Table 6, informal care is reported much more frequently than formal care. Within the informal care group, Table 7 shows that most of that care comes from others living in the household with the respondent.

Table 5 shows the percentage of respondents who receive each of the four different kinds of in-home help and how many hours per week each was received. Nearly three in ten respondents (about 30%) reported receiving informal care in their homes from spouse, family, or friends who live with them. Respondents received about 17 hours of this kind of help per week in a typical week, with most reporting more than five hours per week. About 14% of respondents reported receiving informal care from family, friends, or neighbors who do not live with them. Respondents received about 11 hours of this kind of care per week in a typical week, with about one-fourth reporting an hour or less and two in five reporting more than five hours per week.

Approximately 7% of respondents reported that they received formal care from an agency, paid person, personal care assistant or attendant, or a volunteer. They reported receiving an average of 11 hours of this kind of care per week in a typical week, with slightly more than half reporting fewer than five hours per week. Very few respondents (2%) received professional nursing care in their homes, with most of them (80%) reporting an hour or less of nursing care per week.

Table 5. In-home care by source of care given

	Percent receiving (n=571)*	Mean hours in a typical week**
From spouse, family, friends living with them	29.8%	17
From family, friends, neighbors not living with them	14.1%	11
From agency, paid care, personal attendant/assistant, volunteer	7.1%	11
From professional nursing care	2.0%	3
No help from any of the four sources	60.6%	NA

* The number of unweighted cases varies from 570-571, depending on the number of missing cases.

** The number of unweighted cases varies depending on how many respondents reported receiving each type of care. The numbers vary from 12 (for professional nursing care) to 161 (for spouse, family friends living with them).

Table 6. In-home care – formal versus informal

	Percent receiving (n=570)
Formal care only	2.3%
Informal care only	31.5%
Both formal and informal care	5.6%
No help from any of the four sources	60.6%

Table 7. In-home care – informal

	Percent receiving (n=570)
Informal care from only those living with them	23.0%
Informal care from only those not living with them	7.2%
Informal care from both those living with them and those not living with them	6.8%
No informal care	63.0%

Three of five respondents reported that they receive no help from any of the four sources. They were asked about possible unmet needs, and about 7% (representing about 4% of all respondents) said that they need help with health care, personal care, or tasks of daily living. Table 8 shows percentages of persons currently not receiving help who reported needing in home care, followed in the second column by the numbers based on the full sample.

Table 8. In home care needed by people currently not receiving care

	Not receiving help but need in home care (n=34)	Based on the full sample (n=571)
A few times a month or less	40.2%	1.6%
1-2 hours per week	22.2%	1%
3-5 hours per week	30.8%	1%
More than 5 hours per week	6.8%	<1%

Respondents who already receive some help at home were asked if they get all the help they need or if they need more. One third (37%) of those currently receiving some help said that they could use more help (approximately 14% of the full sample). This group reported needing more hours of help than the group currently not receiving help at all, as shown in Table 9.

Table 9. In home care needed by people currently receiving care

	Receiving help but need more in home care (n=85)	Based on the full sample (n=571)
1-2 hours per week	7.4%	1%
3-5 hours per week	28.7	4%
6-10 hours per week	27.4	4%
More than 10 hours per week	36.4	5%

Respondents were asked why they were not getting the help they needed. For most respondents not getting any help but needing it, the reason they were not getting the help they needed was cost or noncoverage by insurance (75%). Half of respondents in this group (who were about 4% of the total sample) also reported that the quality of care available (57%) and not knowing where to look (53%) were barriers. For respondents getting some in-home help, the reported reasons for not getting the help they needed were similar: cost or non-coverage by insurance (78%), quality of care available (29%), not knowing where to look (57%), and not being able to find help (31%).

Most respondents who were receiving in-home help of some kind did not spend anything for that care (79%). Respondents who did spend something reported spending on average \$298 for that

care in the past 12 months. About 58% of those who did have out-of-pocket care expenses reported that this spending was very or somewhat difficult.

Home-Delivered Meals

Fewer than 1% of respondents reported that they received home-delivered meals. Among the majority who did not receive them, about 5% reported that they feel like they need them. Those who felt like they needed them reported needing an average of 6 meals per week, with most reporting that they needed either just a couple (27%) or at least seven meals per week (28%). Over three-fourths of respondents who would like home-delivered meals (79%) reported that the reason they did not receive them is that they did not know how to arrange it. About one third (35%) reported that cost is the reason they were not currently receiving home-delivered meals.

Case Management

The survey contained a number of questions regarding unmet needs for case management. This is a difficult area to measure, as there does not seem to be consistent terminology in use by potential recipients, and case management is a term used in many social service contexts. Respondents were not asked directly about case management, but instead were asked about several specific kinds of assistance or services that can be components of case management. If the respondent did not receive that service in the past 12 months, he/she was asked if they felt like they needed that help. Table 10 shows the percentage of respondents in the full sample who said that they needed different kinds of specific help from a case manager.

Table 10. Percent who needed case management services in the past 12 months

Felt like needed	% (n=571)
Help keeping track of services	19.6%
Help finding services	19.5%
Advice about eligibility for public benefit programs	18.3%
Help finding caregivers to help at home	15.2%

Information

One possible area of unmet need is for information about services; that is, adults with health problems or disabilities may not know where to get the information they need about different possible options. In a number of places in the survey, lack of information was offered as a possible reason for a specific unmet need. In addition, the survey contained some general questions about accessing information and the need for additional information. About 13% of respondents reported having received information about services in the past 12 months from a social worker or case manager. About 11% reported receiving such information from an organization that helps people with health conditions or disabilities, such as Easter Seals, the MS Society, or similar groups. About 13% reported receiving services information from a state or other government agency. However, among respondents who did not report getting information from a government agency, nearly two-thirds (62%) said they did not know of any state agency

or other government agency that provides information about services to people with a health problem or disability.

Respondents were also asked about not getting information they needed, and about one third (34%) reported that they wanted to get information about services for people with a health problem or disability but did not know where to get it. One-fourth of respondents (25%) said that they wanted information about legal rights for people with their health problem or disability but did not know where to get it.

Recreation and Exercise

Nearly four of five survey respondents (78%) reported that they did some kind of regular physical exercise. Few, though, participated in a physical recreation program, such as a sports league or group physical activity (12%). Those who did not participate in a recreation program were asked if they would like to and if so, why they did not participate. About half said they would like to participate in such an activity (47%), but they did not because of cost (51%), they did not know how to arrange it (43%), there were no such places or programs nearby (32%), the programs were not designed for people with disabilities (30%), or they could not get there (21%).

Transportation

About 17% of respondents reported having had a transportation problem getting where they needed to go in the past 12 months. Most of that group (77%) said it was very or somewhat difficult getting where they would like to go. When asked about possible kinds of assistance with transportation that would make it easier to get where they wanted to go, about 12% suggested better access to good public transportation for people with disabilities and about 12% suggested better information about available transportation options. Fewer reported that vehicle adaptations would help (about 2%).

One in ten respondents reported having used transportation services for persons with disabilities in the past year; about 4% used The Ride, the Paratransit program that provides door-to-door service to people with disabilities living in selected communities in Massachusetts. For respondents who did not use transportation services for persons with disabilities in the past 12 months, about 13% said they wanted to. Of those, about half (47%) said that they knew of such transportation service, but the rest were unaware of such services. Among respondents who knew about the services but did not use them, reasons for not utilizing the services included: lack of knowledge about how to contact such services (58%), the service did not meet their needs (33%), the cost (30%), or they did not think they were eligible for such services (25%). (Note that these percentages represent just 1-3% of the full sample.)

All respondents were asked specifically if they ever wanted to use public transportation in the past 12 months but did not do so and why. About 15% said they wanted to but did not, and most reported that the stations or stops were too far from their house (9% of respondents overall) or the schedule did not meet their needs (6%). Others said it was the cost (3%), lack of information (3%), or lack of wheelchair accessibility (1%).

Access to Care

The survey asked about times respondents needed health care but did not get it and why. The questions were asked with respect to primary care providers, medical specialists, and mental health doctors or counselors. Table 11 summarizes the percentage of respondents who did not have sufficient access to medical care and the reasons why.

The reason mentioned most frequently for not getting needed medical care was difficulty figuring out who to see. Aside from the reasons asked about directly in the survey and shown in Table 11, respondents offered other reasons, including not being able to get appointments with doctors when they needed them (having to wait months to get in), child care problems, and lack of health insurance.

Table 11. Access to care

	From primary care provider	From medical specialist	From mental health worker
Percentage who did not get care when needed it (n=570)	20.4%	20.6%	18.5%
<i>Reasons for not getting care (based on those who did not get care when needed it)*</i>			
Cost	22.2%	32.7%	33.9%
Difficulty figuring out who to see	38.8%	40.8%	56.9%
Hard to leave home	34.8%	21.2%	42.1%
Did not have transportation	21.0%	14.0%	20.5%
Office not physically accessible for person with disability	1.3%	2.9%	2.4%

* The number of unweighted cases varies depending on how many respondents reported not getting the needed care. The numbers vary from about 97 (for mental health care) to about 132 (for medical specialist care), though they vary by one or two cases, depending on the number of missing values.

Respondents were asked directly if their health condition or disability resulted in any problems getting the health care they needed in the past 12 months, and 8% said that it had. About one-third of them (35%) said that the provider was not knowledgeable about their disability. About one-fourth of them (26%) said that the equipment at the health care facility was not accessible, and 12% said that the site itself was not physically accessible. Approximately 17% said the provider could not communicate with them.

Hospital, Nursing Home, Rehabilitation

About one-third of all respondents (33%) were hospitalized for at least one night in the past 12 months. The average number of nights (including the people who said none), was approximately 3 nights. Among respondents who were not hospitalized, about 9% said there was a time when they or their doctor thought they needed hospitalization during the past 12 months, but they weren't hospitalized. A follow-up question asked about the reasons they weren't hospitalized. While about 12% said the reason was cost or insurance, most said it was some other reason.

Likewise, respondents who had not stayed in a nursing home or rehabilitation center in the past 12 months were asked if they or their doctor ever thought that was needed. Only about 1% of respondents said yes, they needed a nursing home or rehabilitation stay but did not get one.

Physical and Occupational Therapy

About one-third of respondents (34%) reported seeing a physical or occupational therapist in the past 12 months; however, about one-fourth of them (26%) said that they did not get as much therapy as they needed. Of that group, about 60% said the reason was cost or that insurance would not cover it. The two-thirds of respondents who had not had any physical or occupational therapy in the past 12 months were asked if they needed it and if so, why they did not get it. About 8% of all respondents did not get the needed therapy, and of that group, about 35% said it was because of cost or insurance would not cover it. Another 26% said they had difficulty figuring out who to see.

Prescription Drugs

Almost nine of ten respondents (87%) reported taking prescription medication. About 13% of respondents reported that there is a medication that they need but that they did not get. Two-thirds of this group (66%) said that the reason they were not able to get all the prescription medications they needed is the cost and/or insurance will not cover it.

On average, respondents spent nearly \$5500 out of pocket in the past 12 months for their medications, with over 60% of them spending in excess of \$1000 per year. While about half of respondents said that it was not difficult at all to afford out-of-pocket payments for prescriptions, about 30% said it was very or somewhat difficult.

Work Accommodations

About half the survey respondents were employed for pay at the time of survey administration. Of those, nearly one-third (33%) reported that their health condition or disability made it very or somewhat difficult to work in their current job. About one-third of the currently employed (33%) also reported that they needed their employer to make accommodations because of their health condition or disability. Of those needing any accommodation, about three-fourths (75%) reported that their employer had done most or all of what they could do. About one in ten said their employer had done none of what they could do. Respondents who said that their employers had done at least some of what they could do were asked how difficult it had been to get their employer to make accommodations. Six in ten said it was not difficult at all, about two in ten said it was a little difficult, 16% said it was somewhat difficult, and a small proportion (3%) said it was very difficult.

Appendix A: Methodology

Survey Development and Pretesting

The Center for Survey Research, the Massachusetts Department of Public Health (MDPH), and members of the Disability Policy Consortium (DPC) worked together to develop the survey content. The first step was to review what other kinds of data have been collected about caregiving needs and to decide which content areas to cover in the 30-minute survey. Once the general content areas were identified, we tried to use questions that had been used in previous surveys. After agreeing on a draft, CSR conducted six cognitive interviews to help understand if respondents were all interpreting the questions as intended. The respondents for the cognitive interviews were recruited through flyers posted on the UMass Boston campus, advertisements posted on the web, and word of mouth. After the cognitive interviews, CSR proposed extensive revisions to the questionnaire. Again, once the group agreed on a re-draft, CSR conducted an initial pretest of 10 telephone interviews using a random sample of cases received from the BRFSS (see explanation of the sample below). Nine of the 10 pretest interviews were taped and CSR behavior coded the interactions between interviewer and respondent to flag questions that were not working as expected (with a straightforward back-and-forth between interviewer and respondent). After the first pretest, CSR proposed modest revisions to the questionnaire, which were agreed upon by the group and tested in a second telephone pretest with 10 respondents, also a random sample from the BRFSS sample. Very minor changes were made to the questionnaire following the second pretest.

Sample

The sample population for this survey consisted of a subset of respondents to the 2007 Massachusetts Behavioral Risk Factor Surveillance System (BRFSS). We used BRFSS cases that had been interviewed between January and August 2007. Following are the eligibility criteria for the Unmet Needs Study:

- BRFSS respondent was aged 18-59 years at the time of the BRFSS interview.
- Respondent said Yes to at least one of the two BRFSS questions about disability –
 - *Are you limited in any way in any activities because of physical, mental, or emotional problems?*
 - *Do you now have any health problem that requires you to use special equipment, such as a cane, a wheelchair, a special bed, or a special telephone?*
- At the end of BRFSS interview, respondent agreed to being called back for a follow-up interview.

In addition, we included only cases that had been interviewed on the BRFSS in English.

Once the household was reached, we attempted to identify the BRFSS participant:

- *About X months ago, a man/woman in this household, who was [age] years old at the time, participated in a survey for the health department about health and health practices and gave permission to be re-contacted for a follow-up interview. Is that person available?*

Once that person was identified, we re-screened using the two BRFSS disability questions, plus one additional question:

A disability can be physical, mental, emotional, or communication-related. Would you describe yourself as having a disability of any kind?

A respondent answering Yes to this question, or to either of the two original BRFSS disability questions, was considered interview-eligible. All other respondents were deemed ineligible and the interviews were terminated.

There were 1,120 BRFSS cases that met the eligibility criteria including agreeing to be recontacted. These cases were submitted for possible interview. The following table is a complete disposition of the sample numbers.

Table A1. Disposition of telephone numbers in sample⁵

	#	%
STARTED WITH	1,120	
Unable to locate BRFSS respondent or bad phone number	130	
Able to locate	990	
Found to be ineligible (language or did not meet disability criteria)	87	
Eligible	903	
Completed screener part of interview	630	
Screening rate (completed/eligible)		.70
Completed the interview	571	
Interview rate (completed interview/completed screener)		.91
Response rate (screening rate x interview rate) ⁶		.63

⁵ This response rate is calculated using American Association for Public Opinion Research (AAPOR) response rate 3. This is the conservative calculation that assumes that all of the non-screened households would have been eligible for interview. If you re-calculate the response rate assuming that the non-screened households were eligible at the same rate as the screened households, the response rate is about 65%. An alternative approach to calculating the response rate is to simply subtract out all the ineligible phone numbers and people (217) and the remainder (903) becomes your response rate denominator of eligible cases. The response rate calculated this way (completed interview, 571) divided by the eligible cases (903) is the same as the conservative calculation in the table, 63%.

⁶ We were interested in whether response rate varied by BRFSS interview month. More lag time between the original interview and the time of the CSR interview could have effects in two directions: it could make respondents more cooperative, as more time had passed, or it could make them less so, because they had forgotten about their agreeing to a follow-up interview. We were also interested in determining if cooperation varied by month as a result of other post-BRFSS surveys that had been fielded at the same time as the Unmet Needs Survey. Using a crude

As noted in the Introduction, it is important to consider who was not included in the survey population when interpreting the results of this analysis. Individuals with the most severe limitations were not included in this study because the BRFSS does not include individuals living in institutions. In addition, the BRFSS methodology precludes anyone from assisting the selected respondent in completing the interview if the selected adult had difficulty participating for any reason.

There are other limitations to the BRFSS sample design and, therefore, the design of the Unmet Needs study which is a subsample of the BRFSS. The BRFSS limitations are described as follows:

... Households that do not have a telephone do not have the opportunity to participate in the survey. Although only two percent of Massachusetts households lack a telephone, almost 10% of households living below poverty lack a phone, based on the 1990 Census.

In addition, a substantial percent of households contacted to participate in the BRFSS did not complete the survey. Although households were telephoned on repeated occasions, interviewers were not always able to reach the randomly selected adult in the household and some adults contacted did not agree to participate in the survey. We would be concerned about a bias in the results if the respondents who participated differed significantly from those not included in the survey. The weighting of the data partially takes into account this non-response.

Finally, all data collected by the BRFSS are based on self-report from the respondents. By its nature, self-reported data may be subject to error for several reasons. An individual may have difficulty remembering events that occurred a long time ago or the frequency of certain behaviors. Some respondents may overreport socially acceptable behaviors and underreport behaviors deemed unacceptable. Disability is a complex and somewhat subjective concept and the same people may characterize their condition differently at different times. In addition, different people may characterize the same condition differently.⁷

One further limitation is that we do not know if the original BRFSS respondents who did not agree to a possible followup interview are different from those who agreed to a followup. In particular, we do not know if they differ in ways that might be associated with the topics covered in the Unmet Needs survey, particularly things related to having a disability. Since we do not have that information, we must interpret the data with caution until a systematic investigation can be done regarding the characteristics of respondents who refused the followup interview request at the end of the BRFSS interview.”

calculation for cooperation (subtracting only ineligible cases from the original sample), we found that there was very little month-to-month variation in response.

⁷ These limitations are described in Appendix 3 (p.71) of “A Profile of Massachusetts Adults with Disabilities, 1998-2000, Results from the Behavioral Risk Factor Surveillance System,” November 2001 (Accessed Feb. 17, 2008)

Survey Administration

Eighteen interviewers and supervisors were trained to work on the study, though twelve of the interviewers conducted the vast majority of the interviews. The interviews were conducted between September 7 and October 29, 2007. The average interview length was 24 minutes, and it took an average of 4 calls to complete an interview.

Weighting and Analysis

CSR used the BRFSS final weight and added a non-response adjustment to create its own final weight. The BRFSS final weight is calculated by the CDC and is described on the BRFSS website as follows:

BRFSS data are directly weighted for the probability of selection of a telephone number, the number of adults in a household, and the number of telephones in a household. A final poststratification adjustment is made for nonresponse and noncoverage of households without telephones. The weights for each relevant factor are multiplied together to get a final weight.⁸

CSR calculated a non-response adjustment based on the response rate for each of the 12 strata in the BRFSS samples, as follows:

Response rate by strata = number of interviews / (total number of cases minus ineligible)

The final CSR weight was calculated as follows:

Final CSR weight = final BRFSS weight / stratum response rate

The CSR final weight was appended to each of the 571 cases in the final data set, and the data shown in this report use the final CSR weights. The total weighted number of cases is 2,874. The percentages shown in this report are unaffected by the arbitrary number of weighted cases, but if future data users are interested in making population projections, DPH would need to provide an estimate of the number of people in the state that have the survey's eligibility characteristics, and the weights would be multiplied by a constant to weight up to the population estimate.

When running statistical tests using these data, it is important to use the complex sample design feature in the statistical package being used in order to get proper confidence intervals that account for sample design effects.

Write-in Entries

The survey allowed volunteered "other" answers for many questions. For example, the survey offered reasons why a particular need was not being met (such as cost or location), but respondents were typically asked if there were other reasons and, if so, those reasons were

⁸ This information is from the Frequently Asked Questions on the BRFSS website authored by the CDC: <http://www.cdc.gov/brfss/faqs.htm#17>. This page was accessed on December 20, 2007.

written down by the interviewer. The “other” responses were included in part for exploratory purposes, since we were not certain that we could identify the possible reasons to precode in advance, and also to give respondents a chance to provide an answer if the pre-coded options did not cover their situation. CSR did not code these write-in entries. They are available on a separate text file for future use, with an ID for matching to the quantitative data. While writing this report, the authors reviewed the write-in entries to see if there were any obvious patterns and used that information as appropriate in this report.

Appendix B: Survey Questions

GENERAL HEALTH

- 1. Overall, how would you rate your health? Would you say it is excellent, very good, good, fair, or poor?**

☐ EXCELLENT
☐ VERY GOOD
☐ GOOD
☐ FAIR
☐ POOR
☐ NA

- 2. How much of the time during the past month has your health limited your social activities, like visiting with friends or close relatives? Would you say . . .**

☐ None of the time
☐ Some of the time
☐ Most of the time or
☐ All of the time?
☐ DON'T KNOW
☐ REFUSED

RESCREEN FOR DISABILITY STATUS using BRESS items

- 3. Are you limited in any way in any activities because of physical, mental, or emotional problems?**

☐ YES
☐ NO
☐ DON'T KNOW
☐ REFUSED

- 4. Do you now have any health problem that requires you to use special equipment, such as a cane, a wheelchair, a special bed, or a special telephone?**

(Include occasional use or use in certain circumstances.)

☐ YES
☐ NO
☐ DON'T KNOW
☐ REFUSED

- 5. Because of any impairment or health problem, do you have any trouble learning, remembering, or concentrating?**

☐ YES
☐ NO
☐ DON'T KNOW
☐ REFUSED

→ If yes to either 3 or 4, proceed with interview at next section. (skip 6)

6. A disability can be physical, mental, emotional, or communication-related. Would you describe yourself as having a disability of any kind?
- ☐ YES
 - ☐ NO
 - ☐ DON'T KNOW
 - ☐ REFUSED

→ IF R ANSWERS YES TO Q6, HE/SHE IS ELIGIBLE TO BE INTERVIEWED.
OTHERWISE, END INTERVIEW.

ACTIVITIES OF DAILY LIVING (ADLS)

INTRO. *Now I'll ask about some everyday activities. I'd like to know whether you have any difficulty doing each one by yourself and without special equipment.*

FIRST ADL

7. Because of a health condition or disability, do you have any difficulty bathing or showering by yourself and without special equipment?

- ☐ YES → skip to 9
- ☐ NO → skip to 12
- ☐ SOMETIMES → skip to 9
- ☐ DOESN'T DO
- ☐ NA → skip to 12

8. Is this because of a health or physical problem?

- ☐ YES
- ☐ NO → skip to 12
- ☐ NA

9. Do you receive help from another person with bathing or showering?

- ☐ YES
- ☐ NO
- ☐ SOMETIMES
- ☐ NA

10. Do you feel like you need help (IF YES/SOMETIMES: more help than you currently receive) with bathing or showering?

- ☐ YES
- ☐ NO
- ☐ SOMETIMES
- ☐ NA

11. Because of your health condition or disability, do you use special equipment to help you bathe or shower?

- ☐ YES
- ☐ NO
- ☐ SOMETIMES
- ☐ NA

SECOND ADL

12. Do you have any difficulty dressing by yourself and without special equipment?

- ☐ YES → skip to 14
- ☐ NO → skip to 17
- ☐ SOMETIMES → skip to 14
- ☐ DOESN'T DO
- ☐ NA → skip to 17

13. Is this because of a health or physical problem?

- ☐ YES
- ☐ NO → skip to 17
- ☐ NA

14. Do you receive help from another person with dressing?

- ☐ YES
- ☐ NO
- ☐ SOMETIMES
- ☐ NA

15. Do you feel like you need help (IF YES/SOMETIMES: more help than you currently receive) with dressing?

- ☐ YES
- ☐ NO
- ☐ SOMETIMES
- ☐ NA

16. Because of your health condition or disability, do you use special equipment to help you get dressed?

- ☐ YES
- ☐ NO
- ☐ SOMETIMES
- ☐ NA

THIRD ADL

17. Do you have any difficulty eating without help and without special equipment?

- ☐ YES → skip to 19
- ☐ NO → skip to 22
- ☐ SOMETIMES → skip to 19
- ☐ DOESN'T DO
- ☐ NA → skip to 22

18. Is this because of a health or physical problem?

- ☐ YES
- ☐ NO → skip to 22
- ☐ NA

19. Do you receive help from another person with eating?

- ☐ YES
- ☐ NO
- ☐ SOMETIMES
- ☐ NA

20. Do you feel like you need help (IF YES/SOMETIMES: more help than you currently receive) with eating?

- ☐ YES
- ☐ NO
- ☐ SOMETIMES
- ☐ NA

21. Because of your health condition or disability, do you use special equipment to help you eat?

- ☐ YES
- ☐ NO
- ☐ SOMETIMES
- ☐ NA

FOURTH ADL

22. Because of a health condition or disability, do you have any difficulty getting in or out of bed or chairs by yourself and without special equipment?

- ☐ YES → skip to 24
- ☐ NO → skip to 27
- ☐ SOMETIMES → skip to 24
- ☐ DOESN'T DO
- ☐ NA → skip to 27

23. Is this because of a health or physical problem?

- ☐ YES
- ☐ NO → skip to 27
- ☐ NA

24. Do you receive help from another person getting in or out of bed or chairs?

- ☐ YES
- ☐ NO
- ☐ SOMETIMES
- ☐ NA

25. Do you feel like you need help (IF YES/SOMETIMES: more help than you currently receive) with getting in or out of bed or chairs?

- ☐ YES
- ☐ NO
- ☐ SOMETIMES
- ☐ NA

26. Because of your health condition or disability, do you use special equipment to help you get in or out of bed or chairs?

- ☐ YES
- ☐ NO
- ☐ SOMETIMES
- ☐ NA

FIFTH ADL

27. Do you have any difficulty walking by yourself and without special equipment?

- ☐ YES → skip to 29
- ☐ NO → skip to 32
- ☐ SOMETIMES → skip to 29
- ☐ DOESN'T DO
- ☐ NA → skip to 32

28. Is this because of a health or physical problem?

- ☐ YES
- ☐ NO → skip to 32
- ☐ NA

29. Do you receive help from another person with walking?

- ☐ YES
- ☐ NO
- ☐ SOMETIMES
- ☐ NA

30. Do you feel like you need help (IF YES/SOMETIMES: more help than you currently receive) with walking?

- ☐ YES
- ☐ NO
- ☐ SOMETIMES
- ☐ NA

31. Because of your health condition or disability, do you use special equipment to help you walk?

- ☐ YES
- ☐ NO
- ☐ SOMETIMES
- ☐ NA

SIXTH ADL

32. Do you have any difficulty using the toilet by yourself and without special equipment?

- ☐ YES → skip to 34
- ☐ NO → skip to 37
- ☐ SOMETIMES → skip to 34
- ☐ DOESN'T DO
- ☐ NA → skip to 37

33. Is this because of a health or physical problem?

- ☐ YES
- ☐ NO → skip to 37
- ☐ NA

34. Do you receive help from another person with using the toilet?

- ☐ YES
- ☐ NO
- ☐ SOMETIMES
- ☐ NA

35. Do you feel like you need help (IF YES/SOMETIMES: more help than you currently receive) with using the toilet?

- ☐ YES
- ☐ NO
- ☐ SOMETIMES
- ☐ NA

36. Because of your health condition or disability, do you use special equipment to help you use the toilet?

- ☐ YES
- ☐ NO
- ☐ SOMETIMES
- ☐ NA

INSTRUMENTAL ACTIVITIES OF DAILY LIVING (IADLS)

INTRO *Now I'm going to ask about some other everyday activities and whether you have any difficulty doing them by yourself.*

FIRST IADL

37. Because of a health condition or disability, do you have any difficulty doing light housework like washing dishes, straightening up, or light cleaning by yourself?

- ☐ YES → skip to 39
- ☐ NO → skip to 41
- ☐ SOMETIMES → skip to 39
- ☐ DOESN'T DO
- ☐ NA → skip to 41

38. Is this because of a health or physical problem?

- ☐ YES
- ☐ NO → skip to 41
- ☐ NA

39. Do you receive help from another person with doing light housework?

- ☐ YES
- ☐ NO
- ☐ SOMETIMES
- ☐ NA

40. Do you feel like you need help (IF YES/SOMETIMES: more help than you currently receive) with doing light housework?

- ☐ YES
- ☐ NO
- ☐ SOMETIMES
- ☐ NA

SECOND IADL

41. Because of a health condition or disability, do you have any difficulty doing heavy housework like scrubbing floors or washing windows by yourself?

- ☐ YES → skip to 43
- ☐ NO → skip to 45
- ☐ SOMETIMES → skip to 43
- ☐ DOESN'T DO
- ☐ NA → skip to 45

42. Is this because of a health or physical problem?

- ☐ YES
- ☐ NO → skip to 45
- ☐ NA

43. Do you receive help from another person with doing heavy housework?

- ☐ YES
- ☐ NO
- ☐ SOMETIMES
- ☐ NA

44. Do you feel like you need help (IF YES/SOMETIMES: more help than you currently receive) with doing heavy housework?

- ☐ YES
- ☐ NO
- ☐ SOMETIMES
- ☐ NA

THIRD IADL

45. Because of a health condition or disability, do you have any difficulty preparing your own meals by yourself?

- ☐ YES → skip to 47
- ☐ NO → skip to 49
- ☐ SOMETIMES → skip to 47
- ☐ DOESN'T DO
- ☐ NA → skip to 49

46. Is this because of a health or physical problem?

- ☐ YES
- ☐ NO → skip to 49
- ☐ NA

47. Do you receive help from another person with preparing your own meals?

- ☐ YES
- ☐ NO
- ☐ SOMETIMES
- ☐ NA

48. Do you feel like you need help (IF YES/SOMETIMES: more help than you currently receive) with preparing your own meals?

- ☐ YES
- ☐ NO
- ☐ SOMETIMES
- ☐ NA

FOURTH IADL

49. Because of a health condition or disability, do you have any difficulty shopping for things you need, like groceries or medicines, by yourself?

- ☐ YES → skip to 51
- ☐ NO → skip to 53
- ☐ SOMETIMES → skip to 51
- ☐ DOESN'T DO
- ☐ NA → skip to 53

50. Is this because of a health or physical problem?

- ☐ YES
- ☐ NO → skip to 53
- ☐ NA

51. Do you receive help from another person with shopping?

- ☐ YES
- ☐ NO
- ☐ SOMETIMES
- ☐ NA

52. Do you feel like you need help (IF YES/SOMETIMES: more help than you currently receive) with shopping?

- ☐ YES
- ☐ NO
- ☐ SOMETIMES
- ☐ NA

FIFTH IADL

53. Because of a health condition or disability, do you have any difficulty managing money like keeping track of expenses or paying bills by yourself?

- ☐ YES → skip to 55
- ☐ NO → skip to 57
- ☐ SOMETIMES → skip to 55
- ☐ DOESN'T DO
- ☐ NA -> skip to 57

54. Is this because of a health or physical problem?

- ☐ YES
- ☐ NO → skip to 57
- ☐ NA

55. Do you receive help from another person with managing money?

- ☐ YES
- ☐ NO
- ☐ SOMETIMES
- ☐ NA

56. Do you feel like you need help (IF YES/SOMETIMES: more help than you currently receive) with managing money?

- ☐ YES
- ☐ NO
- ☐ SOMETIMES
- ☐ NA

ASSISTIVE TECHNOLOGY

57. INTERVIEWER CHECK: DID R SAY YES AT EITHER Q4, 11, 16, 21, 26, 31, OR 36?

☐ YES

☐ NO → skip to 59a

58. Because of your health condition or disability, what kind of special equipment do you use?

Do you use...

	YES	NO	NA
a. A power wheelchair or scooter?			
b. How about a manual wheelchair?			
c. A walker?			
d. A cane, brace, or forearm crutch?			
e. A wheelchair accessible van or car?			
f. A communication device such as a special telephone, TTY, or video replay?			
g. Some other special equipment? → h. IF YES, What kind of equipment do you use? ____			

58a. INTERVIEWER CHECK: DID R SAY YES TO WHEELCHAIR OR SCOOTER (a or b), OR TO CAR OR VAN (e)?

☐ YES

☐ NO → skip to 59b

58b. In the past 12 months, have you needed any repairs on your [wheelchair or scooter/accessible car or van]?

☐ YES

☐ NO → skip to 59b

☐ NA → skip to 59b

58c. During that time, were you ever totally without a way to get around?

☐ YES → skip to 59b

☐ NO → skip to 59b

☐ NA → skip to 59b

59a. Earlier you said you didn't use any kind of special equipment because of your health condition or disability.

Is there any special equipment that you need for your health condition or disability but that you do not have?

☐ YES → skip to 59c

☐ NO → skip to 62

☐ NA → skip to 62

59b. Is there any other special equipment that you need for your health condition or disability but that you do not have?

☐ YES

☐ NO → skip to 60

☐ NA → skip to 60

59c. What equipment do you need? (DO NOT READ, CHECK ALL THAT APPLY.)

☐ CANE, BRACE, OR FOREARM CRUTCH

☐ COMMUNICATION DEVICE (e.g., SPECIAL PHONE, TTY, VIDEO REPLAY)

☐ HOSPITAL BED

☐ MANUAL WHEELCHAIR

☐ MOTORIZED WHEELCHAIR OR SCOOTER

☐ OXYGEN OR VENTILATOR

☐ WALKER

☐ WHEELCHAIR ACCESSIBLE VAN OR CAR

☐ OTHER EQUIPMENT (SPECIFY: _____)

☐ NA

59d. We are interested in why you are not able to get the equipment you need. Are you unable to get the equipment . . .

	YES	NO	NA
a. ...because of the cost?			
b. [IF NO TO COST] ...because insurance won't cover it?			
c. ...because you don't know where to get it?			
d. ...because it is not available in your community?			
e. ...for some other reason? (SPECIFY) _____			

IF USES EQUIPMENT:

60. Thinking about all the cost of the medical equipment you have used, about how much money did you pay out-of-pocket for this equipment in the past 12 months?

\$_____ TOTAL OUT-OF-POCKET → skip to 61

☐ NONE → skip to 62

☐ DON'T KNOW

☐ REFUSED → skip to 62

60a. Would you say that your total out-of-pocket expenses in the past 12 months for medical equipment were ...

- ☐ Less than \$1,000
- ☐ \$1,000 to \$5,000
- ☐ \$5,000 to \$10,000 or
- ☐ More than \$10,000?
- ☐ DON'T KNOW
- ☐ NA

61. Thinking about all of your out-of-pocket expenses for medical equipment in the past 12 months, how difficult was it for you to afford these payments? Would you say they were very difficult, somewhat difficult, a little difficult, or not difficult at all to afford?

- ☐ Very difficult
- ☐ Somewhat difficult
- ☐ A little difficult
- ☐ Not difficult at all
- ☐ NA

ADAPTING ENVIRONMENT

62. Because of your health condition or disability, have you ever needed any adaptations to your current home, such as ramps, door widening, or special kitchen or bathroom fittings?

- ☐ YES
- ☐ NO → skip to 63
- ☐ NA → skip to 63

62a. Have all of the adaptations been made that would be helpful to you or do you currently need more?

- ☐ MADE ALL → skip to 63
- ☐ NEED MORE
- ☐ IN THE PROCESS OF DOING → skip to 63
- ☐ NA

62b. Are any of the following reasons why all the adaptations that would be helpful to you have not been made? Have they not been made (READ A)...

	YES	NO	NA
a. ... because of the cost?			
b. ... because you live in a rental unit that you aren't allowed to change?			
c. ... because the structure can't be adapted to your needs?			

62c. Are there any other reasons why all the adaptations that would be helpful to you have not been made?

- ☐ YES
- ☐ NO → skip to 62e
- ☐ NA → skip to 62e

62d. What are the reasons? _____

62e. Do you think that getting information about how to pay for adaptations would be helpful to you, or do you have all the information you need about paying for adaptations?

- ☐ MORE INFORMATION WOULD BE HELPFUL
- ☐ HAVE ALL INFORMATION NEEDED
- ☐ NA

HOME CARE

63. Because of your health condition or disability, do you currently receive any help in your home with personal care or daily activities from your spouse, family or friends who live with you?

- ☐ YES
- ☐ NO → skip to 64
- ☐ SOMETIMES
- ☐ NA → skip to 64

63a. About how many hours of help do you receive from them in a typical week?

- _____ hours per week/day/month → skip to 64
- ☐ DON'T KNOW
 - ☐ NA

63b. Is it about....

- ☐ An hour or less each week
- ☐ Two to five hours per week
- ☐ Or more than five hours per week?
- ☐ NA

64. Because of your health condition or disability, do you currently receive any help in your home with personal care or daily activities from family, friends, or neighbors not living with you?

- ☐ YES
- ☐ NO → skip to 65
- ☐ SOMETIMES
- ☐ NA → skip to 65

64a. About how many hours of help do you receive from them in a typical week?

- _____ hours per week/day/month → skip to 65
- ☐ DON'T KNOW
 - ☐ NA

64b. Is it about....

- ☐ An hour or less each week
- ☐ Two to five hours per week
- ☐ Or more than five hours per week?
- ☐ NA

65. Because of your health condition or disability, do you currently receive any help in your home with personal care or daily activities from someone from an agency, a paid person, a personal care attendant or assistant, or a volunteer?

- ☐ YES
- ☐ NO → skip to 66
- ☐ SOMETIMES
- ☐ NA → skip to 66

65a. About how many hours of help do you receive from them in a typical week?

- _____ hours per week/day/month → skip to 66
- ☐ DON'T KNOW
 - ☐ NA

65b. Is it about....

- ☐ An hour or less each week
- ☐ Two to five hours per week
- ☐ Or more than five hours per week?
- ☐ NA

66. Because of your health condition or disability, do you currently receive any professional nursing care in your home?

- ☐ YES
- ☐ NO → skip to Q68check
- ☐ SOMETIMES
- ☐ NA → skip to Q68check

66a. About how many hours of professional nursing care do you receive from them in a typical week?

- _____ hours per week/day/month → skip to Q68check
- ☐ DON'T KNOW
 - ☐ NA

66b. Is it about....

- ☐ An hour or less each week
- ☐ Two to five hours per week
- ☐ Or more than five hours per week?
- ☐ NA

Q68check.
CHECK ITEM:
IF 63 AND 64 AND 65 AND 66 ARE NO, CONTINUE WITH 67a;
ELSE, SKIP TO 68.

(FOR RS WHO REPORT NO HELP)

67a. Even though you do not usually receive help, do you need any help with health care, personal care, or tasks of daily living?

☐ YES

☐ NO → skip to care check

☐ NA → skip to care check

67b. Would you say you need help every day or nearly every day, at least once a week, a few times a month, or once a month or less?

☐ EVERY DAY OR NEARLY EVERY DAY

☐ AT LEAST ONCE A WEEK

☐ A FEW TIMES A MONTH → skip to 67d

☐ ONCE A MONTH OR LESS → skip to 67d

☐ NA → skip to 67d

67c. About how many hours per week of help do you think you would need?

_____ hours per week

☐ NA

67d. We are interested in why you are not able to get the help you need. Are you unable to get the help (READ A)...

	YES	NO	NA
a. ... because of the cost?			
b. [ONLY IF NO TO COST] ...because insurance won't cover it?			
c. ... because of the quality of care available?			
d. ... because you don't know where to look for help?			
e. ... because you know where to look but cannot find help?			

67e. Are there any other reasons why you are not able to get the help you need?

☐ YES

☐ NO → skip to care check

☐ NA → skip to care check

67f. What are the reasons?

_____ → skip to care check

(FOR RS WHO GET HELP BUT REPORT 0 HOURS, DO NOT USE THE “TYPICAL WEEK” FILL)

68. Now thinking about all the help you receive (in a typical week), do you get all the help you need or do you need more?

☐ GET ALL HELP THAT IS NEEDED → skip to 68e

☐ NEED MORE

☐ NA → skip to 68e

68a. About how many more hours per week do you need help?

_____ hours per week

☐ NEED OCCASIONAL HELP, NOT EVERY WEEK

☐ NA

68b. We are interested in why you are not able to get all the help you need. Are you unable to get all the help you need (READ A)...

	YES	NO	NA
a. ... because of the cost?			
b. [ONLY IF NO TO COST] ...because insurance won't cover it?			
c. ... because of the quality of care available?			
d. ... because you don't know where to look for help?			
e. ... because you know where to look but cannot find help?			

68c. Are there any other reasons why you are not able to get all the help you need?

☐ YES

☐ NO → skip to 68e

☐ NA → skip to 68e

68d. What are the reasons? _____

68e. Thinking about all the in-home help that you have received in the past 12 months, about how much money did you pay out-of-pocket for this help?

\$_____ TOTAL OUT-OF-POCKET every month/every 12 months → skip to 68g

☐ NONE → skip to caregiver check item

☐ DON'T KNOW

☐ NA

68f. Would you say that your total out-of-pocket expenses in the past 12 months were...

- ☐ Less than \$1,000
- ☐ \$1,000 to \$5,000
- ☐ \$5,000 to \$10,000 or
- ☐ More than \$10,000?
- ☐ DON'T KNOW
- ☐ REFUSED

68g. Thinking about all of your out-of-pocket expenses for in-home help in the past 12 months, how difficult was it for you to afford these payments? Would you say they were very difficult, somewhat difficult, a little difficult, or not difficult at all to afford?

- ☐ VERY DIFFICULT
- ☐ SOMEWHAT DIFFICULT
- ☐ A LITTLE DIFFICULT
- ☐ NOT DIFFICULT AT ALL
- ☐ NA

Care check.

CHECK ITEM FOR ELIGIBILITY FOR THE CAREGIVER STUDY:

Anyone with at least one ADL or IADL AND reports some hours in 63a or 64a should be flagged for the caregiver screening request at the end of the interview.

COMMUNITY BASED SERVICES – HOME DELIVERED MEALS

69. In a typical week, do you get any meals from a home delivery service like Meals on Wheels or a community organization?

- ☐ YES
- ☐ NO → skip to 69f
- ☐ NA → skip to 69f

69a. About how many home-delivered meals do you usually receive per week?

_____ meals per week

- ☐ DON'T KNOW
- ☐ NA

69b. Do you feel like you need more meals delivered each week?

- ☐ YES
- ☐ NO → skip to 70a
- ☐ NA → skip to 70a

69c. About how many more home-delivered meals do you think you need each week?

_____ more meals per week

- ☐ DON'T KNOW
- ☐ NA

69d. Why aren't you able to get more home delivered meals? Is it...

	YES	NO	NA
a. ...because of the cost?			
b. ...because you do not know how to arrange it?			
c. ...because you were told you are not eligible?			
d. ...for some other reason? (SPECIFY) _____			

→ skip to 70a

69f. Do you feel like you need home-delivered meals?

☐ YES

☐ NO → skip to 70a

☐ NA → skip to 70a

69g. About how many home-delivered meals do you think you need each week?

_____ meals per week

☐ DON'T KNOW

☐ NA

69h. Why aren't you able to get home delivered meals. Is it...

	YES	NO	NA
a. ...because of the cost?			
b. ...because you do not know how to arrange it?			
c. ...because you were told you are not eligible?			
d. ...for some other reason? (SPECIFY) _____			

COMMUNITY BASED SERVICES – CASE MANAGEMENT

70a. I'm going to read a list of different kinds of help that organizations or agencies sometimes provide to people with a health condition or disability. For each one, please tell me if it is something that you have received for yourself in the past 12 months.

In the past 12 months, did any agency or organization help you find the services you need for yourself?

☐ YES → skip to 70c

☐ NO

☐ NA → skip to 70c

70b. Did you feel like you needed that help in the past 12 months?

☐ YES

☐ NO

☐ NA

70c. In the past 12 months, did any agency or organization help you organize or keep track of the services you receive for yourself?

☐ YES → skip to 70e

☐ NO

☐ NA → skip to 70e

70d. Did you feel like you needed that help in the past 12 months?

☐ YES

☐ NO

☐ NA

70e. In the past 12 months, did you receive any advice from any agency or organization about your eligibility for public benefit programs, like SSI, SSDI, Disability, or Medicaid?

☐ YES → skip to 70g

☐ NO

☐ NA → skip to 70g

70f. Did you feel like you needed that advice in the past 12 months?

☐ YES

☐ NO

☐ NA

70g. In the past 12 months, did any agency or organization help you find caregivers to help you in your home?

☐ YES → skip to 71

☐ NO

☐ NA → skip to 71

70h. Did you feel like you needed that help in the past 12 months?

☐ YES

☐ NO

☐ NA

INFORMATION

71. In the past 12 months, have you gotten any information about services for people with your health condition or disability (READ A) ...

	YES	NO	NA
a. ... from a social worker or case manager?			
b. ...from an organization that helps people with health conditions or disabilities, such as Easter Seals, the MS Society, the Parkinson's Association, the Spinal Cord Injury Association, or any group like that?			
c. ... from a state agency or other government agency?			

IF NO TO STATE AGENCY (c)

71a. Do you know of any state agency or other government agency that provides information about services to people with a health condition or disability?

☐ YES

☐ NO

☐ NA

72a. In the past 12 months, was there any time when you wanted to get information about services for people with your health condition or disability but did not know where to get it?

☐ YES

☐ NO

☐ NA

72b. In the past 12 months, was there any time when you wanted to get information about legal rights for people with your health condition or disability but did not know where to get it?

☐ YES

☐ NO

☐ NA

COMMUNITY BASED SERVICES – RECREATION AND EXERCISE

73. Do you do any kind of regular physical exercise, including physical therapy or exercises [or walking]?

- ☐ YES
- ☐ NO
- ☐ NA

74. Do you participate in any kind of physical recreation program, such as a sports league or other type of group physical activity?

- ☐ YES → skip to 75
- ☐ NO
- ☐ NA → skip to 75

74a. Would you like to participate in some kind of physical recreation program?

- ☐ YES
- ☐ NO → skip to 75
- ☐ NA → skip to 75

74b. Are any of the following reasons why you are not able to participate?

	YES	NO	NA
a. ...because of the cost?			
b. ...because you do not know how to arrange it?			
c. ...because you cannot get there?			
d. ...because there are no places or programs nearby?			
e. ...because the programs are not designed for persons with health conditions or disabilities?			

74c. Are there any other reasons why you are not able to participate in a physical recreation program?

- ☐ YES
- ☐ NO → skip to 75
- ☐ NA → skip to 75

74d. What are the reasons? _____

TRANSPORTATION

75. Now I have some questions about how you get places outside your home. In the past 12 months have you had any difficulty getting where you would like to go outside your home?

☐ YES

☐ NO → skip to 76

☐ NA → skip to 76

75a. Is that because of transportation problems or for some other reason?

☐ TRANSPORTATION PROBLEMS

☐ SOME OTHER REASON (SPECIFY): _____ → skip to 76

☐ BOTH - TRANSPORTATION PROBLEMS & OTHER REASON

(SPECIFY OTHER REASON): _____

☐ NA

75b. How difficult has it been for you to get where you would like to go? Would you say it has been very difficult, somewhat difficult, or only a little difficult?

☐ Very difficult

☐ Somewhat difficult

☐ A little difficult

☐ NA

75c. Would any of the following kinds of assistance with transportation make it easier for you to go places? (READ A)...

	YES	NO	NA
a. Adaptations to your vehicle?			
b. Better access to good public transportation for people with disabilities?			
c. Better information about what transportation is available for you?			

76. In the past 12 months, have you used any transportation services provided for persons with disabilities, such as from a volunteer organization, para transit, The Ride, or anything else?

- ☐ YES
- ☐ NO → skip to 76b
- ☐ NA → skip to 76b

76a. What did you use? (Mark all that apply.)

- ☐ Para transit → skip to 77
- ☐ The Ride → skip to 77
- ☐ Volunteer organization → skip to 77
- ☐ Other. Specify: _____ → skip to 77

76b. In the past 12 months, was there any time when you wanted to use a transportation service for people with disabilities, but did not?

- ☐ YES
- ☐ NO → skip to 77
- ☐ NA → skip to 77

76c. Do you know of any such services in your area?

- ☐ YES
- ☐ NO → skip to 77
- ☐ NA → skip to 77

76d. Are any of the following reasons why you didn't use the service?

	YES	NO	NA
a. The cost of using it?			
b. You don't know how to contact such services?			
c. You are not eligible for the services?			
d. The schedule did not meet your needs?			
e. You didn't think the service was good?			

76e. Are there any other reasons why you didn't use the service?

- ☐ YES
- ☐ NO → skip to 77
- ☐ NA → skip to 77

76f. What are the reasons?

77. In the past 12 months, have you ever wanted to use public transportation, such as local bus, subway, or train service, but did not?

☐ YES

☐ NO → skip to 78

☐ NA → skip to 78

77a. What kept you from using public transportation? Was it ...

	YES	NO	NA
a. The cost?			
b. Public transportation is not wheelchair accessible?			
c. The stations or stops are too far from your home?			
d. You don't have information you need about public transportation?			
e. The schedule did not meet your needs?			

77b. Are there any other reasons why you didn't use public transportation?

☐ YES

☐ NO → skip to 78

☐ NA → skip to 78

77c. What are the reasons? _____

ACCESS TO CARE

78. A **primary care provider** is a general doctor or nurse or physician's assistant who takes care of a wide range of common problems. In the past 12 months, was there any time when you thought you needed to see a primary care provider but did not do so?

☐ YES

☐ NO → skip to 79

☐ NA → skip to 79

- 78a. Was that (READ A)...

	YES	NO	NA
a. ...because of the cost?			
b. ...because you had difficulty figuring out who to see?			
c. ...because it is hard for you to leave your home?			
d. ...because you did not have transportation?			
e. ...because the office was not physically accessible for a person with a disability?			
f. ...for some other reason? (SPECIFY) _____			

79. **Medical specialists** are doctors like surgeons, heart doctors, allergy doctors, skin doctors, and other doctors who specialize in one area of health care. In the past 12 months, was there any time when you thought you needed to see a medical specialist, but did not do so?

☐ YES

☐ NO → skip to 80

☐ NA → skip to 80

- 79a. Was that (READ A)...

	YES	NO	NA
a. ...because of the cost?			
b. ...because you had difficulty figuring out who to see?			
c. ...because it is hard for you to leave your home?			
d. ...because you did not have transportation?			
e. ...because the office was not physically accessible for a person with a disability?			
f. ...for some other reason? (SPECIFY) _____			

80. In the past 12 months was there any time you thought you needed to see a psychiatrist, psychologist, or mental health counselor, but did not do so?

☐ YES

☐ NO → skip to 81

☐ NA → skip to 81

80a. Was that (READ A)...

	YES	NO	NA
a. ...because of the cost?			
b. ...because you had difficulty figuring out who to see?			
c. ...because it is hard for you to leave your home?			
d. ...because you did not have transportation?			
e. ...because the office was not physically accessible for a person with a disability?			
f. ...for some other reason? (SPECIFY) _____			

81. Sometimes people with a health condition or disability tell us that their health care providers are not providing the health care they need. For example, doctors' offices sometimes are not equipped with exam tables that the patient can get onto or a routine test such as a mammogram isn't administered to a woman in a wheelchair. In the past 12 months, has having a health condition or disability resulted in any problems getting the health care you need?

☐ YES

☐ NO → skip to 82

☐ NA → skip to 82

81a. In the past 12 months, did you experience any of the following problems getting the health care you needed?

	YES	NO	NA
the health care provider site was not physically accessible?			
the equipment at the healthcare facility was not physically accessible?			
the provider could not communicate with you?			
the provider was not knowledgeable about your health condition or disability?			

81b. Did you experience any other problems getting the health care you needed?

☐ YES

☐ NO → skip to 82

☐ NA → skip to 82

81c. What was the problem? _____

HOSPITAL AND NURSING HOME/REHAB CARE

82. During the past 12 months how many nights were you hospitalized because of illness or injury?

_____ # NIGHTS/WEEKS/MONTHS → skip to 83

☐ DON'T KNOW → skip to 83

☐ NONE

☐ NA → skip to 83

82a. Was there any time in the past 12 months that you or your doctor thought you needed to be hospitalized?

☐ YES

☐ NO → skip to 83

☐ NA → skip to 83

82b. What was the reason you were not hospitalized? Was it that you could not afford the hospital costs, because your insurance wouldn't cover the cost, or was there some other reason?

☐ COULD NOT AFFORD

☐ INSURANCE WOULD NOT COVER

☐ SOME OTHER REASON

☐ NA

83. In the past 12 months, did you stay in a nursing home, a physical rehabilitation hospital, or a physical rehabilitation unit of a hospital?

☐ YES → skip to 84

☐ NO

☐ NA → skip to 84

83a. Was there any time in the past 12 months that you or your doctor thought you needed to stay in a nursing home, a physical rehabilitation hospital, or a physical rehabilitation unit of a hospital?

☐ YES

☐ NO → skip to 84

☐ NA → skip to 84

83b. What was the reason you did not? Was it that you could not afford the costs, your insurance wouldn't cover the cost, or was there some other reason?

☐ COULD NOT AFFORD

☐ INSURANCE WOULD NOT COVER

☐ SOME OTHER REASON

☐ NA

PHYSICAL AND OCCUPATIONAL THERAPY

84. In the past 12 months, did you see a physical or occupational therapist?

☐ YES → skip to 84c

☐ NO

☐ NA → skip to 85

84a. Did you or your doctor feel you needed to?

☐ YES

☐ NO → skip to 85

☐ NA → skip to 85

84b. Why weren't you able to see one? Was it (READ A)...

	YES	NO	NA
a. ...because of the cost?			
b. [ONLY IF NO TO COST] ...because insurance won't cover it?			
c. ...because you had difficulty figuring out who to see?			
d. ...because it is hard for you to leave your home?			
e. ...because you did not have transportation?			
f. ...because the office was not physically accessible for a person with a disability?			
g. ...for some other reason? (SPECIFY) _____			

→ skip to 85

84c. Did you get as much physical or occupational therapy as you needed in the past 12 months?

☐ YES → skip to 85

☐ NO

☐ NA → skip to 85

84d. Why weren't you able to get as much physical or occupational therapy as you or your doctor felt you needed in the past 12 months? Was it (READ A)...

	YES	NO	NA
a. ...because of the cost?			
b. [ONLY IF NO TO COST] ...because insurance won't cover it?			
c. ...because you had difficulty figuring out who to see?			
d. ...because it is hard for you to leave your home?			
e. ...because you did not have transportation?			
f. ...because the office was not physically accessible for a person with a disability?			
g. ...for some other reason? (SPECIFY) _____			

TYPE OF INSURANCE

85. Do you have any health insurance?

- ☐ YES
☐ NO
☐ NA

86. Do you have any health coverage through government programs, such as Medicare, Medicaid, MassHealth, CommonHealth, or Veteran's health coverage?

- ☐ YES
☐ NO
☐ NA

CHECK ITEM

- ☐ NO INSURANCE (85 AND 86 = NO) → ASK 86a
☐ PUBLIC INSURANCE (86 = YES) → SKIP TO 87
☐ OTHER → SKIP TO CURRENTLY COVERED BY MORE THAN ONE Q (Q90)
☐ UNABLE TO ANSWER (85 AND 86 = NA) → SKIP TO 91

86a. Just to confirm, you currently have no health insurance at all. Is that correct?

- ☐ YES → SKIP TO 91
☐ NO (FIND OUT WHAT THEY HAVE HERE AND EDIT 85 AND 86)
☐ NA → SKIP TO 91

87. Through what government program or programs do you have health coverage (CommonHealth, MassHealth, Medicaid, Medicare, Veteran's/VA health coverage, or something else)? [CHECK ALL THAT APPLY]

- ☐ COMMONHEALTH
- ☐ MASSHEALTH
- ☐ MEDICAID
- ☐ MEDICARE
- ☐ VETERAN'S/VA HEALTH COVERAGE
- ☐ SOMETHING ELSE (SPECIFY): _____
- ☐ NA

88. In addition to (FILL FROM 87), do you have private health insurance or a Medigap plan?

- ☐ YES
- ☐ NO
- ☐ NA

89. CREATE VARIABLE:

- ☐ PUBLIC ONLY (86=Yes and 88=No) → skip to 91
- ☐ PRIVATE ONLY (85=Yes and 86=No) → ask 90
- ☐ BOTH (86=Yes and 88=Yes) → skip to 91

90. Are you currently covered by more than one health insurance policy or program?

- ☐ YES
- ☐ NO
- ☐ NA

DRUGS

91. Do you take any prescription medication?

- ☐ YES
- ☐ NO
- ☐ NA

91a. Are there any prescription medications that you need but that you do not get?

- ☐ YES
- ☐ NO → skip to 92
- ☐ NA → skip to 92

91b. What was the reason you have not been able to get all the prescription medications you need? Was it that you could not afford the costs, your insurance wouldn't cover the cost, or was there some other reason?

- ☐ COULD NOT AFFORD
- ☐ INSURANCE WOULD NOT COVER
- ☐ BOTH
- ☐ SOME OTHER REASON → What was the reason?
- ☐ NA

92. Thinking about all the prescriptions that you have received in the past 12 months, about how much money did you pay out-of-pocket for these prescriptions?

\$_____ TOTAL OUT-OF-POCKET every month/every 12 months → skip to 93

☐ NONE → skip to 94

☐ NO PRESCRIPTIONS IN PAST 12 MONTHS → skip to 94

☐ DON'T KNOW

☐ NA

92a. Would you say that your total out-of-pocket expenses in the past 12 months for prescription medications were...

☐ Less than \$100

☐ \$100 to \$500

☐ \$500 to \$999

☐ \$1,000 to \$2500 or

☐ More than \$2,500?

☐ DON'T KNOW

☐ NA

93. Thinking about all of your out-of-pocket expenses for prescription medications in the past 12 months, how difficult was it for you to afford these payments? Would you say they were very difficult, somewhat difficult, a little difficult, or not difficult at all to afford?

☐ VERY DIFFICULT

☐ SOMEWHAT DIFFICULT

☐ A LITTLE DIFFICULT

☐ NOT DIFFICULT AT ALL

☐ NA

SSI/SSDI

94. Do you currently receive any payments from the government through SSI or SSDI?

DEFINITIONS IF NEEDED:

Security Income (SSI) is monthly Social Security payments for people with disabilities who also have low incomes or have never worked.

Social Security Disability Insurance (SSDI) is monthly Social Security payments for people with disabilities who have worked and paid money into Social Security.

☐ YES

☐ NO

☐ NA

DISABILITY STATUS

95a. What is the impairment or health condition that causes your disability or affects your day-to-day activities the most? (DO NOT READ: if R names more than one, ask for MAJOR one. If can't choose, use first mention.)

- | | |
|---------------------------|-----------------------------------|
| <01> ARTHRITIS/RHEUMATISM | <14> MEMORY, REMEMBERING, |
| <02> ASTHMA | FORGETTING, ALZHEIMER'S |
| <03> BACK OR NECK PROBLEM | ALZHEIMER'S DISEASE, DEMENTIA |
| <04> CANCER | <15> MENTAL ILLNESS/MENTAL HEALTH |
| | PROBLEM |
| <05> DIABETES | <16> MULTIPLE SCLEROSIS (M.S.) |
| <06> EPILEPSY, SEIZURE | <17> OBESITY, OVERWEIGHT, WEIGHT |
| DISORDER, SEIZURES | <18> OTHER LUNG/BREATHING PROBLEM |
| <07> EYE/VISION PROBLEM | (E.G., COPD, EMPHYSEMA, |
| | BRONCHITIS) |
| <08> FRACTURES, BONE | <19> SLEEP DISORDER |
| OR JOINT INJURY | (E.G., INSOMNIA, SLEEP APNEA) |
| <09> HEART PROBLEM | <20> STROKE PROBLEM |
| <10> HEARING PROBLEM | <21> STRESS, WORRY, |
| <11> HYPERTENSION/ | NERVOUSNESS, OTHER NON- |
| HIGH BLOOD PRESSURE | SPECIFIC EMOTIONAL DISTRESS |
| <12> JOINT REPLACEMENT | <22> WALKING/MOBILITY PROBLEM |
| <13> LEARNING DISABILITY, | <23> OTHER IMPAIRMENT/CONDITION: |
| DYSLEXIA, ADD OR ADHD, | SPECIFY |
| CONCENTRATION | |
| <77> DON'T KNOW | <99> REFUSED |

95b. For how long have your activities been limited because of your impairment, health condition or disability?

- ___ Days
___ Weeks
___ Months
___ Years

___ DATE STARTED

☐ DON'T KNOW

→ **95c. Would you say it's within the past year, one to five years ago, or more than 5 years ago?**

- ☐ NA
☐ ENTIRE LIFE

96. Do you have any other impairments or health conditions that affect your day-to-day activities? (MARK ALL THAT APPLY, DO NOT READ)

<00> NONE/NO MORE

<01> ARTHRITIS/RHEUMATISM

<02> ASTHMA

<03> BACK OR NECK PROBLEM

<04> CANCER

<05> DIABETES

<06> EPILEPSY, SEIZURE
DISORDER, SEIZURES

<07> EYE/VISION PROBLEM

<08> FRACTURES, BONE
OR JOINT INJURY

<09> HEART PROBLEM

<10> HEARING PROBLEM

<11> HYPERTENSION/
HIGH BLOOD PRESSURE

<12> JOINT REPLACEMENT

<13> LEARNING DISABILITY,
DYSLEXIA, ADD OR ADHD,
CONCENTRATION

<14> MEMORY, REMEMBERING,

FORGETTING, ALZHEIMER'S

ALZHEIMER'S DISEASE, DEMENTIA

<15> MENTAL ILLNESS/MENTAL HEALTH
PROBLEM

<16> MULTIPLE SCLEROSIS (M.S.)

<17> OBESITY, OVERWEIGHT, WEIGHT

<18> OTHER LUNG/BREATHING PROBLEM
(E.G., COPD, EMPHYSEMA,
BRONCHITIS)

<19> SLEEP DISORDER

(E.G., INSOMNIA, SLEEP APNEA)

<20> STROKE PROBLEM

<21> STRESS, WORRY,
NERVOUSNESS, OTHER NON-
SPECIFIC EMOTIONAL DISTRESS

<22> WALKING/MOBILITY PROBLEM

<23> OTHER IMPAIRMENT/CONDITION:
SPECIFY

<77> DON'T KNOW

<99> REFUSED

EMPLOYMENT

97. Are you currently working at a job for pay?

☐ YES → skip to 98

☐ NO

☐ NA → skip to 101

97a. Are you not working or did you stop working because of your health condition or disability or for some other reason?

☐ HEALTH CONDITION OR DISABILITY → skip to 101

☐ SOME OTHER REASON → skip to 101

☐ BOTH → skip to 101

☐ NA → skip to 101

98. How many hours do you work at your job in an average week?

_____ # HOURS

☐ NA

99. How difficult does your health condition or disability make it for you to work in the job you are in now — very difficult, somewhat difficult, a little difficult, or not difficult at all?

- ☐ VERY DIFFICULT
- ☐ SOMEWHAT DIFFICULT
- ☐ A LITTLE DIFFICULT
- ☐ NOT DIFFICULT AT ALL
- ☐ NA

100. Have you needed your employer to make any accommodations because of your health condition or disability?

- ☐ YES
- ☐ NO → skip to 101
- ☐ DOESN'T APPLY - R IS SELF-EMPLOYED [VOL.] → skip to 101
- ☐ NA → skip to 101

100a. In describing how accommodating your employer has been, would you say your employer has done all they could do, most of what they could do, some of what they could do, or none of what they could do?

- ☐ ALL THEY COULD DO
- ☐ MOST OF WHAT THEY COULD DO
- ☐ SOME OF WHAT THEY COULD DO
- ☐ NONE OF WHAT THEY COULD DO → skip to 101
- ☐ NA

100b. How difficult has it been for you to get your employer to make accommodations? Would you say it has been very difficult, somewhat difficult, a little difficult, or not difficult at all for you?

- ☐ VERY DIFFICULT
- ☐ SOMEWHAT DIFFICULT
- ☐ A LITTLE DIFFICULT
- ☐ NOT DIFFICULT AT ALL
- ☐ NA

DEMOGRAPHICS

101. Now I have some questions about your living situation and your background. Are you currently living in a house, an apartment, a condominium, an assisted living residence, or some other place?

- ☐ A HOUSE
- ☐ AN APARTMENT
- ☐ A CONDOMINIUM
- ☐ AN ASSISTED LIVING RESIDENCE
- ☐ SOME OTHER PLACE
- ☐ NA

102. How many other adults age 18 or older live in your household with you?

- _____ # ADULTS
- ☐ NA

103. Do you have any children age 17 or younger who live with you?

☐ YES

☐ NO → skip to 104

☐ NA → skip to 104

103a. How many?

_____ # CHILDREN

☐ NA → skip to 104

103b. (Starting with the oldest,) What is the age of the (oldest/next oldest) child?

CHILD 1 AGE: _____

CHILD 2 AGE: _____

CHILD 3 AGE: _____

CHILD 4 AGE: _____

104. What is your current marital status? Are you married, divorced, widowed, separated, or have you never been married?

☐ MARRIED

☐ DIVORCED

☐ WIDOWED

☐ SEPARATED

☐ NEVER BEEN MARRIED

☐ NA

105. What is your age?

_____ AGE

☐ NA

106. Do you consider yourself to be of Hispanic or Latino origin?

☐ YES

☐ NO

☐ NA

107. Please answer yes or no for each of the following racial or ethnic groups. Which of the following racial or ethnic groups describes you best? [ANSWER YES OR NO FOR EACH]

	YES	NO
Black or African-American	<input type="checkbox"/>	<input type="checkbox"/>
Asian	<input type="checkbox"/>	<input type="checkbox"/>
American Indian or Alaskan Native	<input type="checkbox"/>	<input type="checkbox"/>
Native Hawaiian or Pacific Islander	<input type="checkbox"/>	<input type="checkbox"/>
White	<input type="checkbox"/>	<input type="checkbox"/>
Something else	<input type="checkbox"/>	<input type="checkbox"/>

- 108. What is the highest grade or level of education you have completed?**
☐ LESS THAN HS DIPLOMA
☐ HIGH SCHOOL DIPLOMA
☐ SOME COLLEGE OR TECHNICAL SCHOOL (i.e., Assoc. Degree)
☐ BACHELOR'S DEGREE (B.A.)
☐ MASTER'S DEGREE (M.A.)
☐ DOCTORATE/MEDICAL/LAW DEGREE (PH.D., M.D., J.D.)
- 109. Have you ever served on active duty in the United States Armed Forces, either in the regular military or in a National Guard or military reserve unit?**
☐ YES
☐ NO → skip to 110
☐ NA → skip to 110
- 109a. Do you have a VA disability rating?**
☐ YES
☐ NO → skip to 110
☐ NA → skip to 110
- 109b. What is your VA disability rating?**

☐ DON'T KNOW
☐ NA
- 110. Do you use a computer at home, at work, or anywhere else?**
☐ YES
☐ NO
☐ NA
- 111. INTERVIEWER CHECK: DID R ANSWER 6 AT BEGINNING OF INTERVIEW?**
☐ YES → skip to 113
☐ NO
- 112. A disability can be physical, mental, emotional, or communication-related. Would you describe yourself as having a disability of any kind?**
☐ YES
☐ NO
☐ DON'T KNOW
☐ REFUSED

- 113. In studies like this, families are sometimes grouped according to**
Appendix B, p.36

income. I'm going to read you some categories. Please stop me when I get to the one that best describes your total (family) income in 2006; this means income before taxes from all sources, such as salaries, interest, retirement or any other source (for all family members living in your household).

In 2006, was your total (family) income less than \$30,000, between \$30,000 and \$60,000, between \$60,000 and \$90,000, or more than \$90,000?

- ☐ LESS THAN \$30,000
- ☐ BETWEEN \$30,000 AND \$60,000 → skip to 113b
- ☐ BETWEEN \$60,000 AND \$90,000 → skip to 113c
- ☐ MORE THAN \$90,000 → skip to 113d
- ☐ DON'T KNOW → skip to 114
- ☐ REFUSED → skip to 114

113a. Was it less than \$10,000, between \$10,000 and \$20,000, or more than \$20,000?

- ☐ LESS THAN \$10,000 → skip to 114
- ☐ BETWEEN \$10,000 AND \$20,000 → skip to 114
- ☐ MORE THAN \$20,000 → skip to 114
- ☐ DON'T KNOW → skip to 114
- ☐ REFUSED → skip to 114

113b. Was it less than \$40,000, between \$40,000 and \$50,000, or more than \$50,000?

- ☐ LESS THAN \$40,000 → skip to 114
- ☐ BETWEEN \$40,000 AND \$50,000 → skip to 114
- ☐ MORE THAN \$50,000 → skip to 114
- ☐ DON'T KNOW → skip to 114
- ☐ REFUSED → skip to 114

113c. Was it less than \$70,000, between \$70,000 and \$80,000, or more than \$80,000?

- ☐ LESS THAN \$70,000 → skip to 114
- ☐ BETWEEN \$70,000 AND \$80,000 → skip to 114
- ☐ MORE THAN \$80,000 → skip to 114
- ☐ DON'T KNOW → skip to 114
- ☐ REFUSED → skip to 114

113d. Was it less than \$100,000, between \$100,000 and \$110,000, or more than \$110,000?

- ☐ LESS THAN \$100,000
- ☐ BETWEEN \$100,000 AND \$110,000
- ☐ MORE THAN \$110,000
- ☐ DON'T KNOW
- ☐ REFUSED

114.

INTERVIEWER CHECK: If eligible for caregiver study, skip to 115. If not eligible, end interview.

115. SCREEN FOR CAREGIVER STUDY IF ELIGIBLE

That is the end of our survey questions. If you are willing, we would like to conduct a short interview with the family member, friend, or neighbor who provides you the most care or assistance so that we can learn what additional needs they might have as a caregiver. We will not share your answers with that person; we will be asking them different questions. But we need your permission to speak with them. Would that be okay with you?

☐ YES

☐ NO → end interview

116. So that I know how to refer to you when I talk with them, may I please have your first name?

117. Which one relative, friend, or neighbor provides you the most hours of assistance in a typical week?

_____ name

117a. What is that person's relationship to you?

117b. Would you please tell us what is the best way to contact him/her?

117c. What is the best time of day to contact him/her?

[If R prefers to ask the caregiver him/herself, provide phone number for them to call back or set up callback time to obtain contact information.]

END

>R_under<

INTERVIEWER:

PLEASE ANSWER THE FOLLOWING THREE QUESTIONS TO GIVE US YOUR IMPRESSION OF THE RESPONDENT'S LEVEL OF COMPREHENSION.

How would you rate the respondent's understanding of the questions?

<1> EXCELLENT

<2> VERY GOOD

<3> GOOD

<4> FAIR

<5> POOR

>R_concent<

On a scale of 0 - 10, where 0 means they could not concentrate at all and 10 means they remained concentrated throughout the interview, how would you rate this respondent's concentration throughout the interview?

>R_recall<

How would you rate R's ability to recall information?

<1> NO PROBLEM

<2> SMALL PROBLEM

<3> MODERATE PROBLEM

<4> SEVERE PROBLEM